

The mission of AXYS

To help individuals with one or more extra X or Y chromosomes and their families to live fuller and more productive lives.

AXYS serves individuals and families affected by Sex Chromosome Aneuploidy including:

- 47,XXY (Klinefelter syndrome)
- 47,XYY (Jacobs syndrome)
- 47,XXX (Trisomy X)
- 48,XXYY and 48,XXXY
- 49,XXXXY
- 48,XXXX and 49,XXXXX



Donate to the XXYY Project

The XXYY Project operates as a project of AXYS, a 501(c)(3) organization. We rely on donations to fund our important support, advocacy and education work. Please consider making a tax deductible, online donation to the XXYY Project by visiting the AXYS website and clicking on XXYY Project in the drop-down box.

www.genetic.org/donate/

About the XXYY Project

The XXYY Project was organized by members of the XXYY Parent Network, an informal association of parents, founded in 1998. It currently operates under the umbrella of AXYS, the association of X and Y chromosome variations.

The XXYY Project offers information and support for affected individuals and family members world-wide. XXYY events are held around the world. The Project takes part in the biennial AXYS Family Conferences. The XXYY Project has also been instrumental in expanding the AXYS Clinic and Research Consortium and in promoting research projects into XXYY Syndrome.



Contact the XXYY Project

PO Box 253, Church Hill, MD 21623

1-267-338-4262

xxyyprojectsupport@genetic.org

facebook.com/xxyyproject



What is XYY Syndrome?

Typical males are born with only one X and one Y chromosome. Males with XYY have two of each, for a total of 48 chromosomes. XYY is sometimes written as 48,XYY. This is one of the X and Y chromosome variations, also known as sex chromosome aneuploidy, a difference in the typical number. Approximately one in 17,000-18,000 boys is born with XYY. XYY is a neurodevelopmental disorder.



XYY was once considered to be a variation of Klinefelter syndrome, 47,XXY. Although the two genetic disorders share some symptoms, research has established that XYY has its own distinct characteristics. Symptoms are often more numerous and severe, and may require special treatment and management.

How is XYY diagnosed?

Diagnosis for XYY is done through genetic testing, called a karyotype or a microarray. The test involves a blood sample to analyze chromosomes. In some cases, a male may have some normal XY cells as well as some XYY cells. This is called mosaicism.

What are the symptoms?

XYY is often mistaken for other syndromes. The most common symptoms and characteristics noticeable by parents and medical professionals include:

- *Developmental delay*
- *Speech impairment*
- *Tall stature, considering family history*
- *Behavior outbursts and mood swings*
- *Learning disabilities; possible low IQ*
- *ADHD*
- *Autism spectrum disorder*
- *Allergies, asthma, other respiratory conditions*
- *Tremors*
- *Seizures*
- *Delayed or incomplete puberty*
- *Undescended testicles*
- *Testosterone deficiency*
- *Breast development (gynecomastia)*
- *Infertility*
- *Low muscle tone*
- *Flat feet*
- *Curved little finger (clinodactyly)*
- *Significant dental problems*
- *Cardiac problems*

Not all males with XYY experience all of these symptoms.

Is there a cure?

There is no cure for XYY. However, new research into XYY syndrome is helping to develop treatment that can improve the lives of affected boys and men.

What are possible treatments?

Speech, occupational and physical therapy can be very helpful in decreasing developmental delays. Many boys benefit from special education and structured behavioral programs in school. Medications to address ADHD, anxiety and mood disorders can be helpful. Hormone therapy can be initiated for boys who cannot make adequate testosterone on their own.

Common myths

Many families are distressed to hear frightening myths about XYY. Contrary to what is stated in some old medical texts:

- Not all males with XYY have intellectual disability. Recent research finds that only 26% have IQs below 70.
- Males with XYY are no more likely to display criminal behavior than any other individuals.
- While some males with XYY will require supervised residential placement in adulthood, many can live independently with community supports.
- People with XYY are typically born male, and only rarely have ambiguous genitalia.

